



RESOURCE GAP ANALYSIS REPORT

June 8, 2010

Final



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INTRODUCTION

This document provides an analysis of the potential resources that could be included in a Family Leadership Online Resource Center. It outlines the resources evaluated, the process used to evaluate them, and the findings and recommendations stemming from this analysis. This analysis was done in support of developing an online resource center. Therefore, before detailing the analysis itself, we begin by providing background on the entire project.

Background

Sunny Start, Riley Child Development Center (RCDC), and the Indiana State Department of Health (ISDH) recognize that some families face greater challenges than others because they have higher rates of interactions with formal systems. Some families, because of economic issues, health issues, or a family members' disability, are active stakeholders in and users of formal programs to get their families' needs met.

The need to create strong family leaders, community leaders, and state-level leaders who can advocate on family issues is strong within this population of families. Consequently, Sunny Start, RCDC, and ISDH want to empower this special group of families with the knowledge and skills to:

- Develop effective partnerships with service providers.
- Interact effectively with a broad array of cultural backgrounds, helping them communicate well with people from a variety of socioeconomic, ethnic, and family backgrounds and traditions.
- Find and use resources that can help support the whole family as well as individuals within the family.
- Advocate to get their families' needs met.
- Teach advocacy skills to others.

As a first phase of a broad vision, ISDH funded development of a **leadership competency model** focused on families who have a child or children with disabilities. This model serves as the foundation for creating **an online resource center** to help families:

1. Identify their own leadership goals (e.g. to be a family leader, community leader, or state/national leader).
2. Clarify what leadership looks like at the family, community, and state/national level (e.g. the knowledge and skills associated with leadership).
3. Identify gaps between their current skill set – and the skill set leaders have.
4. Locate training programs, self-study resources, and experiences that can help close gaps.
5. Document their skill and knowledge acquisition, building a “portfolio” that outlines the steps they've completed in developing leadership skills.

As the first step to creating the online resource center, Bottom-Line Performance (BLP) worked with Sunny Start to finalize the competency model (located in the Appendix) and analyze existing resources to see how well they help achieve the competencies and key behaviors defined in the leadership model. This report outlines this analysis process and documents findings and recommendations.



Once the resource center is in place, ISDH wants to move to a second phase that includes a broader group of families such as families involved in First Steps, Head Start, and Healthy Families. The work done in the first phase will be leveraged in this second phase.

NUMBERS POTENTIALLY SERVED BY ONLINE RESOURCE CENTER

On an annual basis, Sunny Start expects an online resource center to support almost a thousand people per year for JUST the first family group (families who have a member with a disability).

- At the “family” level – several hundred per year.
- At the “community” level – between 100 – 200.
- At the state/national level – 40 to 50.



ANALYSIS PROCESS

Step 1: Gather Resources to Evaluate

After we finalized the competency model, Sunny Start staff reached out to all the organizations who partnered in developing the draft competency model. Sunny Start requested any resources that might help someone develop the competencies and key behaviors defined in the model.

Fifty-one different resources were provided by the following organizations:

- About Special Kids (ASK)
- Arc of Indiana
- Autism Society of Indiana
- Families Reaching for Rainbows
- Families United for Support and Encouragement (FUSE)
- Family Voices
- Governor's Planning Council for People with Disabilities (GCPD)
- Hamilton County Autism Support Group
- Hands and Voices
- HEAR Indiana
- Indiana Down Syndrome Foundation
- Indiana Institute on Disability and Community
- IN*SOURCE
- Indiana Federation of Families for Children's Mental Health
- Riley Child Development Center
- Special Kids, Informed Parents
- United Cerebral Palsy
- Individual Advocates



Sunny Start did an initial screening, which eliminated many of the resources due to:

- Age of resource.
- Appropriateness of content (as distilled by being able to view abstracts).
- Ability to access the resource to review it and ability of others to access it without difficulty. (e.g. In several instances, we were provided the name of a resource but no material to review.)

This initial screening reduced the number of resources from 51 to 16 resources to review in more depth. The table below identifies those that received more in-depth review.

Resource Title	Type	Time required to complete	Source
Public Health Insurance: What You Don't Know Can Cost You	Leader-led training	1/2 day	ASK
What Every Parent Wishes You Knew	Leader-led training	1/2 day	ASK
Fact Sheets (e.g. Students With Special Health Care Needs, Schools Billing Medicaid, General Guide to Health Insurance Options, etc.)	Printable quick reference	NA	ASK
Parents as Leaders modules	Online	could not determine	University of Vermont
Family Trainee	Individual mentoring	300 hours over a 1-year period	RCDC
Partners in Living	Online	7 hours	Partners In Policy Making
Partners in Time	Online	8 hours	Partners In Policy Making
Partners in Education	Online	3 hours	Partners In Policy Making
Making Your Case	Online	3 hours	Partners In Policy Making
Partners in Employment	Online	6 hours	Partners In Policy Making
Understanding Article 7: Indiana's Special Education Law	Recorded webinar	3 hours	IN*Source
Educational Surrogate Parent Training	Leader-led /online	3 hours	IN*Source
How to Prepare for Your Student's Special Education Case	Leader-led/online	3 hours	IN*Source



Resource Title	Type	Time required to complete	Source
Conference			
Partners in Policy Making	Leader-led training	9 months	GCPD
Common Sense Parenting	Leader-led training	7 weeks	Reaching for Rainbows
The Family Voices Leadership Guide	Book	Varies, depends on reading ability.	Family Voices

Step 2: Compare Resources to Key Leadership Behaviors in Competency Model

We reviewed each resource against the competency model. We created a matrix, listing the elements of the competency model on the left-hand side of the matrix and listing each resource – along with its objectives or agenda items (when available) across the top. We reviewed the contents of each resource and compared the contents (where possible) to all the behaviors listed in the model. When a “match” appeared to exist, we indicated this in the matrix. (Full matrix available upon request).

Step 3: Rate the resource

For behaviors where a match appeared to exist, we used the following scale to rate how well it matched:

- 1 = fully meets the behavior listed in the model. (Satisfies knowledge and skill-building elements associated with behavior).
- 2 = partially meets the behavior listed in the model. (Satisfies some of the knowledge component; may not address skill-building).
- 3 = minimally meets the behavior in the model. (Less than 25% linkage to the behavior)

Rating the resources was difficult in many instances because the **vast majority of resources provided did not include any type of learning objectives**. This meant we had to cull through content to see if it matched. In other instances, we had great objectives – but no content to match up to the objectives.

Step 4: Formulate Findings and Recommendations

We weighed the ratings and resource received against additional criteria to identify findings and recommendations to offer. Factors we considered:

- Access of the resource to a broad population. (Example: Family Trainee program offered through RCDC is excellent, but it currently has one mentor who accepts a maximum of three people into the program per year.)
- Comprehensiveness of the resource. A resource that only satisfies ONE key behavior out of the numerous ones associated with each competency is probably not a great resource. (Example: Partners in Living, an online course requiring multiple hours to complete, only met one or two of the key behaviors. It makes little sense to include this as a good resource since the time a learner would invest in completing the resource would not equal the benefit gained from it.)



- Perception of how well the target learners would engage with the resource. Many resources contained good content – but this content may be at a high reading grade level or very technical and dry – something that may not appeal to a typical family member.

FINDINGS AND RECOMMENDATIONS

Summary of findings and recommendations

- All content we reviewed was developed prior to creation of competency model – often with a very narrow focus. As a result, the materials often did not align with the competency model.
- Existing resources provide a “fair” amount of support in helping people achieve the competencies associated with family leadership. There are few resources to help someone achieve competencies at the community or state/national levels.
- The biggest limitation of resources available at the “family” level is their focus on knowledge acquisition rather than skill development. None of the resources reviewed at the “family” level of leadership included any skill-building activities. (e.g. role plays, scenarios to work through, etc.)
- Self-study resources (e.g. online courses, books, fact sheets) may be at too high a reading grade level to appeal to many target learners. There do not appear to be any Spanish resources, which is another severe limitation.
- The primary potential source of skill development at the community and state/national levels is a program called Partners in Policy (a series of seminars that span 8 weekends). This COULD be an excellent means of developing community and state/national leaders. However the absence of any content to correlate to the excellent objectives makes it impossible to recommend this program as a viable solution for developing leaders.
- Existing “Partners” online courses are cumbersome to navigate, written at a high reading grade level, and generally lack engaging components (multimedia, graphics, etc.).
- Given the almost complete absence of resources at the community and state/national levels, it appears:
 - > There is a critical need for resource development.
 - > The timing may be inappropriate for development of an online resource center for community-level leadership and above.
- There is a significant opportunity to improve resources, creating materials that are at a more appropriate reading grade level, appeal to those with low literacy levels, meet the needs of Spanish speakers, etc.
- There is a significant need to add “skill-building” components. The focus of almost every resource is on knowledge acquisition with no opportunity for people to practice using the information.

Detailed Findings for Family-Level Competencies and Key Behaviors

As stated in the summary findings, the greatest number of resources is available at the “family” level of leadership. Resources we analyzed that are targeted for use by people focused on their families include:

- ½-day workshop, *What Every Parent Wishes You Knew*.
- 1-day workshop, *Public Health Insurance: What You Don’t Know Can Cost You*.
- Family Voices self-study book.
- *Family to Family Advocacy is not a Bad Word* 1-hour e-course.
- ASK and Sunny Start fact sheets.

What’s not covered through these resources – or is covered in very limited fashion includes:

- Competency: Delivery and Support Systems:



- > Describe assessment and diagnostic tools
- > Navigating the transitions between programs/systems.
- Competency: Advocacy
 - > Promote the use of evidence-based practices and diagnosis and treatment.
 - > Describe the evolution of evidence-based practices.
 - > Identify legal, moral, and practical issues related to evidence-based practices.
- Competency: Cultural Proficiency:
 - > Recognize how attitudes and values related to culture, ethnicity, disability, and family affect interactions.

The table below and on the next page identifies the resources that exist for EACH key behavior. If no resource was identified, we simply listed “Need Resource” in the overall findings column.

Competency Area 1: Family-Provider Partnerships		
Performance	Key Behaviors	Overall Findings
Develop provider-partnership relationships	Identify your family’s needs and strengths and recognize where your family needs support.	Satisfactory way to achieve.
	Model the traits of a provider partnership and ask your child’s providers to help you create a partnership.	Need additional resource to allow for skill practice.
	Recognize the traits of a provider partnership.	Satisfactory way to achieve.
	Describe examples of positive family-provider relationships	Satisfactory way to achieve.
	See your child as a person first and recognize that his/her diagnosis does not define the your child or your family	Satisfactory way to achieve.
Use effective communication strategies	Use the communication modes that are effective with the service organizations you work with.	Need additional resource to allow for skill practice.
	Select the best way to frame messages and requests to get your needs met.	Need additional resource to allow for skill practice.
	When appropriate, use the language (terms, jargons, acronyms) of your child's disability and the service organization(s) that serve your child.	Need additional resource to allow for skill practice.
Competency Area Two: Cultural Proficiency		
Performance	Key Behaviors	Overall Findings
Display cultural proficiency when	Share your family's culture, values, and expertise with your child's providers.	Need additional resource to allow for skill practice.



building provider-partnership relationships	Recognize how attitudes and values related to culture, ethnicity, disability, and family affect interactions. <ul style="list-style-type: none"> · Service agency toward families. · Families toward service agency(ies). 	Limited coverage - need more coverage within existing resources or creation of new resource.
	Acknowledge the influence of your child's diagnosis on your family's culture.	Adequately covered via 1/2 day " <i>What Every Parent Wishes...</i> " workshop.
Competency Area Three: Delivery and Support Systems		
Performance	Key Behaviors	Overall Findings
Find and use needed resources	Describe the assessment and diagnostic tools used to determine the child's disability or special health care need.	Need resource.
	Identify the internal supports and resources that can meet your family's needs.	Adequately covered via Family Voices self-study workbook.
	Identify external supports and resources that meet your family's needs.	Fact sheets provide ample information.
Improve coordination and integration of service delivery systems	Navigates the various transitions the child and family experience from system to system.	Need resource.
Competency Area Four: Advocacy		
Performance	Key Behaviors	Overall Findings
Advocate for emerging evidence-based practices	Promote the use of evidence-based practices in the diagnosis and treatment of their child.	Need resource.
	Describe the evolution of key evidence based practices related to the diagnosis and treatment of their child.	Need resource.
	Identify legal, moral, ethical, and practical issues related to implementation of emerging evidence based practices for their child.	Need resource.
Influence systems to strengthen them	Recognize and use advocacy skills to address your child/family issues.	Need additional resource to allow for skill practice.
	Describe the role of advocacy as it relates to disability and	Satisfactory resources via



	special health care needs	Family Voices workbook and F2F advocacy e-course.
	When appropriate, you can tell your family’s and child’s story in layman’s terms to meet the needs of your audience.	Need additional resource to allow for skill practice.
	Ensure your child has access to the resources and services to which he or she is entitled.	Ideally, another resource might supplement here. Family Voices workbook does provide some information.
Teach advocacy to others.	Explain what advocacy means and provide others with examples of what advocacy includes.	Resources fairly limited here.
	Promote the use of advocacy skills by all members of your family to ensure your child's needs are met.	Resources fairly limited here.

Recommendations for Family-Level Resources

Add fact sheets to cover overview of assessment and diagnostic tools, explanation of evidence-based practice. Ensure these fact sheets are at an 5th or 6th grade reading level.

Add reflective, skill-building component that helps fill out the knowledge delivered via training. This could be accomplished via:

- 1) Create skill-building resource booklets that can be downloaded or viewed online via web page format.
- 2) Develop e-course for role-playing scenarios;
- 3) Extend ½-day parenting workshop to a full-day and add role play elements to it.

Consider the needs of Spanish-speaking family members.

Detailed Findings for Community-and State/National-Level Competencies and Key Behaviors

We analyzed the community-level and state/national-level key behaviors together because the skill set required at the community level is largely the same as that required of a leader at the state level. Scale is different, but key behaviors are mostly the same. If you are proficient at working at the community level, the skills will transfer to working with state/national level.)

In addition to recognizing the value of the family-level resources listed in the previous section, we identified these resources as targeted for use by people focused n developing leadership skills at community level or above.

- Partners in Policy (8 weekend series of seminars).
- Partners Making Your Case 3-hour e-course
- Family Trainee program – one-on-one mentoring program.



Our analysis of resources suitable for development of community-level and state/national-level leaders was significantly hampered. The Partners in Policy program is the **major** way in which most key behaviors are satisfied and we could not evaluate the program’s content – only the stated objectives of the series. The Family Trainee program is excellent, but it is not a viable resource because the number of people who can go through it is very limited on an annual basis. (This year there are three program participants.)

Like the family-level resources, the competencies and key behaviors below are largely untouched by any of the resources currently available.

- Competency: Delivery and Support Systems:
 - > Describe assessment and diagnostic tools
 - > Navigating the transitions between programs/systems.
- Competency: Advocacy
 - > Promote the use of evidence-based practices and diagnosis and treatment.
 - > Describe the evolution of evidence-based practices.
 - > Identify legal, moral, and practical issues related to evidence-based practices.
- Competency: Cultural Proficiency:
 - > Recognize how attitudes and values related to culture, ethnicity, disability, and family affect interactions.

The table below and on the next pages identifies the resources that exist for EACH key behavior. The **gray** cells are behaviors associated with community leaders; the **peach** cells are those associated with state/national levels of leadership. If no resource was identified, we simply listed “Need Resource” in the overall findings column.

Competency Area One: Provider-Partner Relationships		
Performance	Key Behaviors	Findings
Develop provider-partnership relationships	Know the people and organizations in your community that serve families.	Need to develop resource - or provide guidance on how one does this.
	Distinguish effective from ineffective partnership organizations.	Need to develop resource - or provide guidance on how one does this.
	Help promote family-provider partnerships to others.	Need skill-building resource.
	You recognize the traits of a provider partnership.	Covered via Family resources.
	You describe examples of positive family-provider relationships.	Covered via Family resources.
	See children as people first and recognize that their diagnoses do not define them or their families.	Covered via Family resources.



	Know the people and organizations at the state and national level that serve families and can distinguish effective from ineffective partnership organizations.	Need to develop resource - or provide guidance on how one does this.
	Follow the principles of family-provider partnerships as you work with policy-makers and program developers.	If adequate skill-building resources added at Family level, these should provide skills needed.
	Recognize the traits of a provider partnership.	Covered as part of Family resources.
	Describe examples of positive family-provider relationships.	Covered as part of Family resources.
	See children as people first and recognize that their diagnoses do not define them or their families.	Covered as part of Family resources.
Use effective communication strategies	Use the communication modes that are effective with the service organizations you work with.	Need skill-building resource.
	Share your technical knowledge of the varying categories of diagnoses of children with special health care needs in a way that helps others understand needs.	Need skill-building resource.
	When appropriate, use the language (terms, jargons, acronyms) of a child's disability and the service organization(s) that serve children.	Need skill-building resource.
	Use the communication modes that are effective with the legislative groups and program agencies you work with.	Need skill-building resource.
	Share your technical knowledge of the varying categories of diagnoses of children with special health care needs in a way that helps others understand needs.	Need skill-building resource.
	Document and communicate your activities and results to local organizations and individuals.	Need skill-building resource or "best practices" examples.
	When appropriate, use the language (terms, jargons, acronyms) of a child's disability and the service organization(s) that serve children.	Need skill-building resource.



Competency Area Two: Cultural Proficiency

Performance	Key Behaviors	Findings
Display cultural proficiency when building provider-partnership relationships	Recognize how attitudes and values related to culture, ethnicity, disability, and family affect partnerships.	Need resource.
	Use cultural preferences of the local community and its families to guide your interactions.	Need resource.
	Promotes the use of resources that meet families' cultural needs.	Need resource.
	Consider cultural preferences as you develop program policies, procedures, and services.	Need resource.
	Support the development of services and systems that meet the needs of varying family dynamics.	Depends on quality of Partners in Choice seminar materials.

Competency Area Three: Delivery and Support Systems

Performance	Key Behaviors	Findings
Find and use needed resources	Identifies the major categories and variety of diagnoses and trends for children with special health care needs.	Need resource.
	Identifies the local, state, and federal programs, agencies, and initiatives that support and influence the specific diagnoses, disability, or special health care need.	Depends on quality of Partners in Choice seminar materials.
	Assists families, providers, and community members in identifying formal and informal supports, resources, and systems available to them.	Depends on quality of Partners in Choice seminar materials.
	Identifies the major categories and variety of diagnoses and trends for children with special health care needs.	Need resource.
	Identifies the state and federal programs, agencies, and initiatives that support and influence disability or special health care needs.	Depends on quality of Partners in Choice seminar materials.
Improve coordination and	Identify integration points between resources that families use.	Depends on quality of Partners in Choice seminar materials.



integration of service delivery systems	Identify and communicate strategies to ensure smooth transitions.	Depends on quality of Partners in Choice seminar materials.
	Influences policy and program practices that support smooth transitions for children with special health care needs and their families.	Depends on quality of Partners in Choice seminar materials.
Competency Area Four: Advocacy		
Performance	Key Behaviors	Findings
Advocate for emerging evidence-based practices.	Promote the use of evidence based practices in Indiana,	Depends on quality of Partners in Choice seminar materials.
	Describe the history and evolution of key evidence based practices and how they cross the disability and special health care spectrum.	Depends on quality of Partners in Choice seminar materials.
	Describe legal, moral, ethical, and practical issues related to emerging evidence based practices and their implementation in Indiana and nationally.	Depends on quality of Partners in Choice seminar materials.
	Works to incorporate evidence based practice into state and federal policy and programming.	Depends on quality of Partners in Choice seminar materials.
	Describe legal, moral, ethical, and practical issues related to emerging evidence based practices and their implementation in Indiana and nationally.	Depends on quality of Partners in Choice seminar materials.
Influence systems to strengthen them	Identify community needs and use advocacy skills to affect a change.	Depends on quality of Partners in Choice seminar materials.
	Identify the leaders and experts related to the diagnosis, disability or special health care need and how they contribute to current treatments and systems.	Need guidelines on how to do this. The specific leaders related to an individual's disability of focus will vary greatly.
	Promote the use of "people first" and unconditional positive regard throughout the community and in programs and services	Depends on quality of Partners in Choice seminar materials.
	Recognize the impact of the history of the disability movement in Indiana on current advocacy efforts.	Depends on quality of Partners in Choice seminar materials.
	Describe the legal, moral, and ethical issues that	Depends on quality of Partners in



	influence advocacy efforts.	Choice seminar materials.
	Identify and supports advocacy skills in other families and explains how they relate to disability and special health care needs	Depends on quality of Partners in Choice seminar materials.
	Promote access to resources as a critical part of local programs.	Need guidelines on how to do this.
	Identify state or national systems needs and uses advocacy skills to effect a change	Depends on quality of Partners in Choice seminar materials.
	Recognize the impact of the history of the national disability movement on advocacy efforts.	Depends on quality of Partners in Choice seminar materials.
	Identify the state and federal legislation, programs, agencies and initiatives that influence current systems and services	E-courses appear to cover this adequately.
	Participate in decision making activities on boards, councils, etc.	Depends on quality of Partners in Choice seminar materials.
	Promote access to resources as a critical part of state and federal programs.	Depends on quality of Partners in Choice seminar materials.
	Communicate the benefits of internal and external, formal and informal resources and supports for families of children with disabilities and special health care needs.	Depends on quality of Partners in Choice seminar materials.
Teach advocacy skills to others	Explain what advocacy means and provide others with examples of what advocacy includes.	Need resource. University of Vermont materials could be used as source content to create a course.
	Cultivate an environment where advocacy is accepted and embraced.	Need resource. University of Vermont materials could be used as source content to create a course.
	Mentor family members to encourage them to get involved from the local level.	Need resource. University of Vermont materials could be used as source content to create a course.
	Mentor others to encourage new leaders to get involved in state and national leadership roles and initiatives.	Need resource. University of Vermont materials could be used as source content to create a course.



Recommendations:

Ask the Governor's Council on Disability to provide access to content for Partners in Policy program. Create a partnership with this group to update and strengthen this program.

Use online source content from University of Vermont to create a multi-module e-course. This provides the most extensive means of access to the widest pool of people. The Partners in Policy course depends on someone being available for 8 weekends. Online courses can be taken at the convenience of the learner.

In the absence of solid training resources, create a sample plan for skill acquisition that focuses on experiences rather than formal training.



CONCLUDING THOUGHTS

Given the absence or limited “match” of many of the resources for those who want to develop leadership skills at the community or state/national is the logical next step to create an online portal...or is it to develop resources and THEN create the online portal for access? We believe the resource issue needs to be discussed further before portal design and development begins.

At a minimum, the stakeholders need to consider whether a phased approach makes more sense than developing the entire portal at once. A phased approach could mean that stakeholders:

- Create assessment pieces plus some print-based materials that at least provide guidance steps on gaining skill via experiences.
- Create family portion of portal only; add community and state/national levels once resources become available.
- Form a coalition and commit funding to develop a few core resources before starting portal design/development.

BLP Recommendations

Bottom-Line Performance (BLP) was contracted by Sunny Start because of its experience and expertise related to competency modeling, gap analysis, curriculum design, learning design, and development. After completing the competency model and gap analysis, we formulated these conclusions and recommendations

Conclusions	Recommendations
<ul style="list-style-type: none"> • It is not in anyone’s best interest to create a portal before sufficient resources exist to populate it. Sunny Start, RCDC, and any other entities who refer families to the portal risk losing credibility with families if they position the portal as a development tool and resource finder...and few resources exist. • The few resources that do exist are very CONTENT focused rather than outcome or learner focused. They lean heavily toward knowledge sharing rather than skill building. Few family members are likely to become effective communicators, partners, and advocates from using these resources because the resources do not provide skill-building opportunities. • The existing resources do not appear to consider low literacy levels or education levels. • The leadership model lays out a strong set of competencies, skills, and behaviors associated with leadership. Because no resources were developed to specifically address this model, there really aren’t any good resources to help people achieve the competencies in a fairly rapid or coherent fashion. 	<ul style="list-style-type: none"> • Delay the portal and focus on resource acquisition, improvement, and/or development FIRST. • Pool your dollars to maximize the quality and reach of what you do. • Use the competency model to formulate a curriculum design that supports the model. Identify the tools (quick reference guides, web courses, online resources, etc.) that help leaders acquire knowledge and skill. • Prioritize. Determine which competencies are MOST critical and focus on those first. Ensure that skill-building components exist; not just knowledge components. • Once a curriculum design is in place, determine what portions of the curriculum can be built “in-house” using existing resources from collaborating agencies and which pieces should be contracted out. • Consider how social media tools can help meet needs- Facebook page, YouTube channel, etc. • Create an implementation plan. Don’t assume “if we build it, people will come.” Plan now for how you will drive people to the resources and the portal, how you will encourage ongoing use, and how you will routinely update resources and add new ones. Weak



	implementation – not design or development – is what causes most projects to fail.
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APPENDIX – FAMILY LEADERSHIP COMPETENCY MODEL

COMPETENCIES, DEFINITIONS, AND KEY SKILLS

Competency 1: Family-Provider Partnerships

Definition A relationship where the skills and perspectives of all people in the relationship are used in a way that respects, trusts, values, and coordinates their expertise toward common goals and outcomes.

Why it's important Family-provider partnership helps families lead their child's care. Family and professional partnerships help meet the needs of all children – at the family, local, and national levels.

- Key skills**
- Develop family-provider partnerships.
 - Use effective communication strategies with providers

Competency Area 2: Cultural Proficiency

Definition An ability to interact effectively with people of different cultures. Culture includes the wide range of behaviors, ideas, beliefs, attitudes, values, habits, and traditions of a particular group of people. Families, work groups, neighborhoods, organizations – or the subgroups within them - can all have a unique culture. Individuals are influenced by a variety of cultural backgrounds of which they are a part.

Why it's important Successful family-provider partnerships recognize the value that each person's unique background, experiences, and traditions contributes.

- Key skill**
- Display cultural proficiency when building provider relationships and working across systems.

Competency Area 3: Delivery and Support Systems

Definition Programs, formal and informal resources, and organizations that offer services, education, or assistance to help meet specific needs.

Why it's important All families need outside services to support them. These services are most effective when families know how to find and use services. Service systems are most effective when families help develop, implement, and evaluate them.

- Key skills**
- Find and use needed resources.
 - Improve coordination and integration of service delivery systems.

Competency Area 4: Advocacy

Definition Speaking, acting, or writing with or on behalf of a person, an issue, or a need.

Why it's important Advocacy leads to access and improvement in services. Meaningful change does not happen without advocacy

- Key skills**
- Advocate for emerging evidence-based practices.
 - Influence systems to strengthen them.
 - Advocate for effective funding allocation.
 - Teach children to advocate for themselves



DETAILED MODEL

COMPETENCY 1: FAMILY PROVIDER PARTNERSHIPS

KEY SKILL: DEVELOP PARTNERSHIP RELATIONSHIPS

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> Recognize the traits of a provider partnership. Describe examples of positive family-provider relationships. Identify your family’s needs and strengths and recognize where your family needs support. Model the traits of a provider partnership and ask your child’s providers to help you create a partnership. See your child as a person first and recognize that his/her diagnosis does not define your child or your family.
When you lead at the local level you:	<ul style="list-style-type: none"> Know the people and organizations in your community that serve families and can distinguish effective from ineffective partnership organizations. Recognize the traits of a provider partnership. Describe examples of positive family-provider relationships. Help promote family-provider partnerships to others.
When you lead at the state or national level you:	<ul style="list-style-type: none"> Know the people and organizations at the state and national level that serve families and can distinguish effective from ineffective partnership organizations. Follow the principles of family-provider partnerships as you work with policy-makers and program developers. Recognize the traits of a provider partnership. Describe examples of positive family-provider relationships.

KEY SKILL: USE EFFECTIVE COMMUNICATION STRATEGIES.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> Use the communication modes that are effective with the service organizations you work with. Select the best way to frame messages and requests to get your needs met. When appropriate, use the language (terms, jargons, acronyms) of your child’s disability and the service organization(s) that serve your child.
When you lead at the local level you:	<ul style="list-style-type: none"> Use the communication modes that are effective with the service organizations you work with. Share your technical knowledge of the varying categories of diagnoses of children with special health care needs in a way that helps others understand needs. When appropriate, use the language (terms, jargons, acronyms) of a child’s disability and the service organization(s) that serve children.



<p>When you lead at the state or national level you:</p>	<ul style="list-style-type: none"> • Use the communication modes that are effective with the legislative groups and program agencies you work with. • Share your technical knowledge of the varying categories of diagnoses of children with special health care needs in a way that helps others understand needs. • Document and communicate your activities and results to local organizations and individuals. • When appropriate, use the language (terms, jargons, acronyms) of a child’s disability and the service organization(s) that serve children.
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COMPETENCY TWO: CULTURAL PROFICIENCY

KEY SKILL: DISPLAY CULTURAL PROFICIENCY WHEN BUILDING PROVIDER RELATIONSHIPS AND WORKING ACROSS SYSTEMS.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
<p>When you lead in your family you:</p>	<ul style="list-style-type: none"> • Share your family’s culture, values, and expertise with your child’s providers. • Recognize how attitudes and values related to culture, ethnicity, disability, and family affect interactions. Display this awareness two ways: <ul style="list-style-type: none"> ○ Service agency toward families. ○ Families toward service agency(ies). • Acknowledge the influence of your child’s diagnosis on your family’s culture.
<p>When you lead at the local level you:</p>	<ul style="list-style-type: none"> • Recognize how attitudes and values related to culture, ethnicity, disability, and family affect partnerships. • Use cultural preferences of the local community and its families to guide your interactions. • Promotes the use of resources that meet families’ cultural needs.
<p>When you lead at the state or national level you:</p>	<ul style="list-style-type: none"> • Consider cultural preferences as you develop program policies, procedures and services • Support the development of services and delivery systems that meet the needs of varying family dynamics.



COMPETENCY 3: DELIVERY AND SUPPORT SYSTEMS

KEY SKILL: FIND AND USE NEEDED RESOURCES.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> Describe the assessment and diagnostic tools used to determine the child’s disability or special health care need Identify the internal supports and resources that can meet your family’s needs. Identify external supports and resources that meet your family’s needs.
When you lead at the local level you:	<ul style="list-style-type: none"> Identifies the major categories and variety of diagnoses and trends for children with special health care needs Identifies the local, state, and federal programs, agencies and initiatives that support and influence the specific diagnosis, disability or special health care need Assists families, providers, and community members in identifying formal and informal supports, resources and systems available to them.
When you lead at the state or national level you:	<ul style="list-style-type: none"> Identifies the major categories and variety of diagnoses and trends for children with special health care needs Identifies the state and federal programs, agencies and initiatives that support and influence disability or special health care needs.

KEY SKILL: IMPROVE COORDINATION AND INTEGRATION OF SERVICE DELIVERY SYSTEMS.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> Navigates the various transitions the child and family experience from system to system.
When you lead at the local level you:	<ul style="list-style-type: none"> Identify integration points between resources that families use. Identify and communicate strategies to ensure smooth transitions.
When you lead at the state or national level you:	<ul style="list-style-type: none"> Influences policy and program practices that support smooth transitions for children with special health care needs and their families.



COMPETENCY 4: ADVOCACY

KEY SKILL: ADVOCATE FOR EMERGING EVIDENCE-BASED PRACTICES.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> • Promote the use of evidence-based practices in the diagnosis and treatment of their child. • Describe the evolution of key evidence based practices related to the diagnosis and treatment of their child. • Identify legal, moral, ethical, and practical issues related to implementation of emerging evidence based practices for their child.
When you lead at the local level you:	<ul style="list-style-type: none"> • Promote the use of evidence based practices in Indiana, • Describe the history and evolution of key evidence based practices and how they cross the disability and special health care spectrum. • Describe legal, moral, ethical, and practical issues related to emerging evidence based practices and their implementation in Indiana and nationally.
When you lead at the state or national level you:	<ul style="list-style-type: none"> • Works to incorporate evidence based practice into state and federal policy and programming. • Describe legal, moral, ethical, and practical issues related to emerging evidence based practices and their implementation in Indiana and nationally.

KEY SKILL: INFLUENCE SYSTEMS TO STRENGTHEN THEM.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
When you lead in your family you:	<ul style="list-style-type: none"> • Recognize and use advocacy skills to address your child/family issues. • You can describe the role of advocacy as it relates to disability and special health care needs • When appropriate, you can tell your family’s and child’s story in layman’s terms to meet the needs of your audience. • You ensure your child to the resources and services to which he or she is entitled.
When you lead at the local level you:	<ul style="list-style-type: none"> • Identify community needs and use advocacy skills to affect a change. • Identify the leaders and experts related to the diagnosis, disability or special health care need and how they contribute to current treatments and systems. • Promote the use of “people first” and unconditional positive regard throughout the community and in programs and services • Recognize the impact of the history of the disability movement in Indiana on current advocacy efforts. • Describe the legal, moral, and ethical issues that influence advocacy efforts. • Identify and supports advocacy skills in other families and explains how they relate to disability and special health care needs • Promote access to resources as a critical part of local programs.



<p>When you lead at the state or national level you:</p>	<ul style="list-style-type: none"> • Identify state or national systems needs and uses advocacy skills to effect a change • Recognize the impact of the history of the national disability movement on advocacy efforts. • Identify the state and federal legislation, programs, agencies and initiatives that influence current systems and services • Participate in decision making activities on boards, councils, etc. • Promote access to resources as a critical part of state and federal programs. • Communicate the benefits of internal and external, formal and informal resources and supports for families of children with disabilities and special health care needs.
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KEY SKILL: TEACH ADVOCACY TO OTHERS.

<i>Competency Level</i>	<i>Required knowledge and behaviors</i>
<p>When you lead in your family you:</p>	<ul style="list-style-type: none"> • Explain what advocacy means and provide others with examples of what advocacy includes. • Promote the use of advocacy skills by all members of your family to ensure your child’s needs are met.
<p>When you lead at the local level you:</p>	<ul style="list-style-type: none"> • Explain what advocacy means and provide others with examples of what advocacy includes. • Cultivate an environment where advocacy is accepted and embraced. • Mentor family members to encourage them to get involved at the local level.
<p>When you lead at the state or national level you:</p>	<ul style="list-style-type: none"> • Mentor others to encourage new leaders to get involved in state and national leadership roles and initiatives.